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Abstract

Worldwide, cancer is a leading cause of death and reducing cancer inequalities is an urgent health priority. Attention is turning to factors which sustain cancer survival, including quality of care. Moreover, in recent policy initiatives, the vision is for care personalised to individual need representing a cultural shift to recovery, health and well-being. This paper discusses a knowledge exchange project that transferred findings from an empirical study, which revealed distinctive patient experiences among lesbian and bisexual (LB) women, to inform the work of two UK national cancer charities. Participatory Action Research methods, involving service users, nursing and other professionals, were key to ensuring outputs were grounded in service user experiences and their involvement lent authority with stakeholders. The project sought to maximise the impact of social science research; embed equality in institutional cultures and practices; influence policy and develop wider knowledge economies about LB women's health. Adopting the Consolidated Framework for Implementation Research, the paper reflects on what works to promote the sustainability of interventions across five domains for enabling knowledge exchange. It contributes to current debates about ways of achieving impact of research on policymaking and practice and to questions about the co-production of knowledge.

Keywords: sexual orientation and gender identity; cancer inequalities; co-production; research impact; knowledge exchange; participatory research.

Introduction

Cancer remains a leading cause of death and the UK lags behind other European nations in five-year survival rates (Department of Health, 2014). Attention has turned to wider social factors which influence the illness trajectory and likelihood of survivorship. Differences between individuals' cancer experiences or outcome are known as cancer inequalities and they arise out of demographic characteristics, including sexual orientation (All Party Parliamentary Group on Cancer (APPGC), 2009). International research has revealed that the disease may be more common in Lesbian and Bisexual (LB) women than amongst their heterosexual counterparts and they delay in presenting to their GP with symptoms (e.g. Burkhalter et al. 2011). Due to the lack of formal support groups and targeted health information, they may have a poorer post-diagnosis experience and lower quality of life with cancer (Boehmer et al. 2011).

Nurses comprise the largest group of professionals providing direct care for patients which gives them a key role in addressing cancer inequalities. Nurses and other healthcare providers' attitudes have been postulated as contributing factors to these disparities (Dorsen, 2012). However, the nursing curriculum appears to lack content relevant to Lesbian, Gay, Bisexual and Trans (LGBT) health concerns providing nursing students with few opportunities to develop understanding and skills in culturally competent care (Lim et al. 2014). Furthermore, a review of articles published in the ten leading nursing journals found that only 8 articles, from a total of 5,000, focussed on LGBT health from scholars in Norway, Sweden, Canada, Ireland and New Zealand with none from the USA or UK (Eliason et al.

2010). Nurses make crucial contributions to cancer care including the ability to assess patients' holistic needs, showing empathy for patients and their families and acting as an advocate across the whole care pathway. In these ways, they can make a significant difference to LGBT cancer patient experience. In the near absence of existing literature and practice based resources to inform cancer nursing practice (see RCN, no date for an exception), this project aimed address these gaps in the knowledge base.

In recent years there has been increasing discussion about the impact and use of research evidence to inform the design and delivery of public services. The turn to evidence-based policy and practice is motivated by twofold concerns: to locate research findings at the heart of policymaking and that public money spent on research should have future benefits for civil society (Martin, 2010). The so-called 'crisis' in utilising research has been ascribed to a 'clash of cultures' between practitioners/ policy makers on the one hand and social science researchers, on the other, who 'inhabit very different worlds', have divergent agendas and competing views about what constitutes good research (Martin, 2010; 212). Academics are said to value conceptual and theory driven research while practitioners require studies that produce instrumental knowledge to enable services to respond to complex social issues. Negotiating this tension, which lies at the heart of translating research findings into healthcare practice, is fundamental to the process of promoting new ways of working. Although the evidence-based practice agenda gained momentum in the UK under New Labour, other governments, including Canada, New Zealand and Australia are concerned to increase the impact of research in the delivery of public services (Mitton et al. 2007). Generating knowledge that has an impact on health care is a continuing UK government commitment promoted, for example, by the Research Excellence Framework, the exercise which assesses research quality in UK universities. To further this agenda, the

Economic and Social Research Council (ESRC) established funding programmes to encourage the transfer or exchange of research findings between the producers and users of knowledge. Knowledge Exchange projects aim to maximise the impact of social science research outside of academia and to use the findings to make a demonstrable contribution to society; for example by increasing the effectiveness of public service delivery and thereby enhancing health, quality of life and well being. Other benefits, which have particular relevance for this project, include improving equity in service delivery (Donovan and Hanney, 2011). Key questions include: how do we encourage the use of research? what do we mean by use? and how do we know what benefits that use has led to? Nutley et al. (2008) argue that research use is 'rarely a straightforward process of simple application to policy and practice decision-making' (2008; 33), but rather it lies on a continuum from awareness, through knowledge and understanding, attitudes, perceptions and ideas to practice and policy change. In this model, the conceptual knowledge favoured by academics is not dichotomised with the instrumental research preferred by practitioners; in order to be used, research needs to engender awareness that a problem exists, create an environment where attitude change occur and support practitioners to develop the knowledge, skills, values, and equip them with tools and resources which facilitate new ways of working (Author, 2010a). This paper contributes to these debates drawing on the experience gained from an ESRC funded Knowledge Exchange (KE) project which aimed to make an impact on national cancer policy and on the provision of cancer support for lesbian and bisexual (LB) women in two national mainstream voluntary sector agencies.

Knowledge Exchange: Project aims and epistemologies

This paper reports on two linked projects which spanned a three year period (2009-2012): the first was a small-scale exploratory study, commissioned by the National Cancer Action Team, *Coming Out about Breast Cancer* which comprised of 18 interviews with LB women with breast cancer and informal carers whose partners had died from the disease (Author, 2010b). Ethical approval was received from the Health and Life Sciences, Research Ethics Committee of xxx university. Findings revealed distinct concerns about treatment and care, in particular: heterosexism in cancer services, interactions with health professionals, coming out, accessing information and support and women's embodied sense of self following surgery. The second project, funded by the ESRC Knowledge Exchange programme, sought to translate the findings of the first study to inform the provision of care in two national cancer Voluntary and Community Services (VCS). This project constitutes the action-oriented component of the research which aimed to develop organisational cultures and practices in voluntary sector based cancer services and to influence cancer policy.

Lesbian and bisexual women with breast cancer may be described as invisible in cancer services. Using Nutley et al's (2008) continuum of types of knowledge illustrates the necessity of engaging with meanings embedded in the construct of LB women's cancer inequalities and introducing the term in organisational discourses. In order to implement change in service delivery, Knowledge Exchange projects must first engender awareness that a problem exists. Producing this kind of conceptual knowledge about lesbian and bisexual women's experiences of the disease was facilitated by the opportunity for discussion presented through the partnership group meetings. While sociological perspectives have highlighted that illness experience is mediated by people's social realities (Lawton, 2003), some professionals did believe that LB women's experiences of breast

cancer would be the same as those of heterosexual women. Previous research has explored the specific issues for men with breast cancer including diagnosis, disclosure and support (Williams et al. 2003). Some professionals involved in this study could acknowledge that men's sense of masculinity is threatened by the disease and recognised that the lack of gender specific information can contribute to their psychological distress (Brain et al. 2006). The recognition that LB women may have different experiences of services and of the disease, however, only emanated through discussion and debate. It occurred over time and culminated at a particularly poignant moment, following feedback upon a disseminated report where a member of a Cancer Network expressed strong views that there was nothing distinctive about the life-worlds of LB women with cancer. The personal experience of heteronormative views added to the overarching purpose of the research in a way that academic discussion is sometimes difficult to achieve. Ontological findings from this study about what it means to be a lesbian or bisexual woman with breast cancer were debated by the partnership group generating epistemologies about their lived experiences of the disease. What does it mean to have breast cancer when your partner is a woman? How does she feel about the prospect of her partner losing her breast? Are female partners more or less empathic? Do they display more or less supportive behaviours? Some of the distinctive issues for lesbian and bisexual women were subtle and nuanced requiring understanding of the complex interplay of their identities, experiences and values in their everyday lives and in their interactions with providers of services. But engendering awareness that a problem exists does not bring about change in working practices. The partnership meetings also generated instrumental knowledge: because discussions took place in a situated context, it was possible to identify practical solutions to some of the emerging problems. Cancer service user members of the partnership group discussed findings where study participants

talked about feeling excluded from cancer support groups because they were unable to disclose their sexual orientation and they experienced difficulties in gaining the emotional support necessary for recovery and survival. Although defining a solution to a specific problem 'represents a widely held view of what research use means' (Nutley et al. 2008; 36), both forms of knowledge were necessary to accomplish knowledge exchange in this project. Without the conceptual knowledge about the nature of lesbian and bisexual women's cancer inequalities and acknowledgement of their distinctive experiences and needs, the practical solutions to problems could not have been implemented.

Methodology and methods

Rationale

The project drew on aspects of Participatory Action Research (PAR) methods which specifically aim to improve health and reduce inequalities. One of the ways in which PAR differs from conventional approaches is that 'that those being researched should be involved in the process actively' (Baum et al. 2006: 854). This principle of integrated knowledge translation, in which the participation of knowledge users, in this case, LB women with cancer and professionals delivering care, contributes to facilitating knowledge use in practice and policymaking. Although such approaches are widely used in breast cancer research (e.g. McCormick et al. 2004) and they have been used in breast cancer research with LB women in Canada (Barnoff et al. 2005), they have not previously been used to facilitate research impact among LB women's communities in the UK.

Participatory research methods underpinned this qualitative study to facilitate a collaborative partnership between 'communities of practice' (Mitton et al. 2007; 737). Participatory methods are grounded in relationships. They offer a distinctive approach to

research by questioning the nature of knowledge and affirming that experience is a legitimate form of knowledge that can lead to change in practice (Baum et al. 2006). Lessons from the service user involvement literature suggest that participatory approaches offer a means of 'strengthening the relevance and appropriateness of research findings' for cancer service users (Wright et al. 2006; 3). The nature of practitioner and service user involvement forms a spectrum from passively providing data to active engagement at most stages of the research. Elsewhere, such approaches are described as a model of 'engaged scholarship' (McCormack, 2011), which facilitate the active engagement of providers and users of services, culminate in knowledge which has been co-produced: they form a strategy which enables debate and dialogue and increases the likelihood of research use.

Partnership group participants

While Knowledge Exchange (KE) projects are sometimes characterised as 'brief one-off linkages' involving a two-way flow of information produced independently by different actors (Mitchell et al. 2009; 105). By contrast, partnership approaches, are exemplified by relationships that are established over time, involve dialogue and produce knowledge in contexts of application. The partnership group, which provided oversight of the original study and the subsequent KE project, included the Director of Research and the Policy officer of a national breast cancer charity; a service user inclusion manager of a national cancer charity; the campaigns officer of a cancer research charity; two London-based LGBT VCS; an Equality and Diversity Manager in the NHS; two academics specialising in cancer; and five cancer service users and carers. Ensuring proximity to the UK centres of policy and decision-making (Nutley et al. 2008) is crucial for determining whether the project is accorded the prestige associated with a national project and this meant it was necessary to

hold steering group meetings in London. Furthermore, both organisations' headquarters were based in the capital, in practical terms, this increased the likelihood that professionals could attend meetings, and these were often held over lunchtimes to encourage participation.

Methods

The partnership group supervised the implementation of the project ensuring that user perspectives of those affected by cancer were strongly represented in the knowledge exchange activities. The partnership was actively involved throughout the 3 year lifespan of the project: contributing to the application for funding, developing research questions, designing the project, analysing the data and communicating the findings.

Design

The ESRC requires that the Knowledge Exchange projects develop a *Pathways to Impact* strategy which informs its decision to allocate funding. It identifies a typical set of impact objectives and these were discussed and refined at partnership group meetings so that the project's aim, of promoting organisational and change, influencing policy and embedding equality in service provision could be achieved for lesbian and bisexual women with cancer.

The four stages are detailed below:

1. Build awareness of the project amongst the target audience of cancer nurses and other professionals:

Stage one aimed to raise awareness of lesbian and bisexual women's cancer inequalities among healthcare professionals and cancer charities and influence policy makers in the UK.

The production of a policy briefing was intended to provide an evidence base, specifically within the breast cancer charity, to inform the organisation of the need to promote cancer equality across its service provision.

2. Secure the commitment of a target group of stakeholders to the project aims:

Stage two began with a sexual orientation and cancer visioning event which formed part of the work of the National Cancer Equalities Initiative (NCEI) and was led by the academic researcher and the deputy chair of the NCEI. The event brought together a number of potential stakeholders from both the LGBT VCS and cancer charities. The resulting partnership group comprised of two cancer charities who committed to implement the interventions and a number of other stakeholder who attended meetings in an advisory capacity.

3. Influence policies or policymakers on key aspects

Spanning a longer time-frame than the lifespan of the project, the contribution to policymaking was an iterative process. The academic researcher had made an input to the Cancer Reform Strategy in 2007 which supported recognition of sexual orientation as a cancer inequality. The recommendations in the *Coming out about Breast Cancer* report identified the Department of Health, NCEI group as policymakers to influence; and the report was presented at a Downing Street reception on *Progress towards beating cancer in this generation* held in 2010. The academic researcher attended the first *National Summit on Cancer in the LGBT Communities* held in New York in 2014; a convening of scientists, clinicians, advocates, and policy experts to address cancer in the LGBT community. The summit formulated a 10 point plan to influence the international LGBT cancer policy and research agenda.

4. Encourage participation among researchers or partner bodies

In stage four, the partnership group took the decision that a learning seminar for nursing and other cancer professionals would facilitate active engagement with the key research messages and provide an environment to develop the values, knowledge and beliefs of

those delivering cancer support in LGBT communities. In this fourth stage, the aim was to produce a good practice resource for dissemination across the workforce.

Evaluating the Pathways to Impact Strategy: findings, outputs and outcomes

Using research to decide a course of action to make an impact on policy and practice has been a central focus since the introduction of the UK national health research strategy (DH, 2006). One typology to promote implementation is the Consolidated Framework for Implementation Research (CFIR) which consists of five domains which are useful for guiding evaluations (Damschroder et al. 2009). In the following sections, these five constructs are examined in relation to the findings, outputs and outcomes from this KE project to critically evaluate the process of implementation.

i) Intervention characteristics

In this KE project, the focus of concern was not a discrete, measurable intervention such as a clinical reminder (e.g. the TLC campaign Touch Look Check) to encourage breast awareness among women. Rather, the project aimed to encourage the active promotion of equality in an organisation's culture and ethos and to inform the delivery of care through healthcare interactions between a cancer professional and a lesbian or bisexual woman with breast cancer. Two intervention-focused resources were developed. The first was a policy briefing aimed at policymakers and cancer organisations which summarised key messages relating to visibility and targeting in breast awareness messaging, access to information, access to emotional support, carers and partners (Available from: <http://www.breastcancercare.org.uk/campaigning-volunteering/policy/breast-cancer->

inequalities/lesbian-bisexual-women-breast-cancer). The second was a good practice resource for cancer and other health professionals. The values, knowledge and skills which underpin effective interactions rely on the confidence of professionals: those who are embarrassed or uncomfortable in providing care to LB women with breast cancer will communicate these emotions to patients. The intervention is thus complex and multi-faceted with many interacting components (e.g. where a professional facilitates the disclosure of sexual orientation or ensures that partners are involved in decision making about treatment and care). Six 'core components' (Damschroder et al. 2009; 3) of health interactions were developed as case studies in the good practice resource: *Supporting LGBT people with cancer*

<http://www.scie.org.uk/workforce/socialcareandhealthinequalities/files/supportinglgbtpeoplewithcancer.pdf> Rather than specifying a formulaic response, the resource presented the issues as discussion points so that the case studies were adaptable to a range of differing scenarios with people.

The CFIR requires attention to the design, quality and packaging of the intervention. Elsewhere, researchers argue that effective KE projects must manage the tension between the expectations in academic reporting of research and in presenting findings to professionals. Practitioners and policymakers look for research to offer practical solutions to problems in everyday healthcare presented in a succinct and accessible way. The development of materials entailed careful attention to images used to represent LB women, the provision of practical action-oriented results and the use of audience appropriate language. The services of a graphic design artist were employed to ensure that the resource was visually appealing.

ii) *Outer setting*

The significance of the *outer setting* (partly alluded to earlier in the paper) for implementing interventions to improve the health and well being of LB women with breast cancer cannot be under-estimated both in the UK and internationally. The human rights of LGBT people, including the right to health, were recognised by the United Nations as recently as September 2012 (UN, 2012). In the UK, public sector bodies had been explicitly prohibited by section 28 of the 1988 Local Government Act from addressing the healthcare issues of LGBT communities apart from the needs of people living with HIV/AIDS (Author, 2009). The political mandate for promoting equality across the public sector (including cancer services) was introduced in the UK by the 2010 Equality Act and reiterated in the policy document *Working for LGBT Equality* (Her Majesty's Government, 2011). The extent to which LB women's needs are known by cancer charities and other organisations has thus been limited by this social and political context; there remains much work to be done in recognising cancer inequalities on the grounds of sexual orientation. For example, the World Health Organisation failed to include sexual orientation and gender identity as a Social Determinant of Health in its groundbreaking report on reducing health inequalities (Logie, 2012). While there has been a watershed in the acceptance of LGBT people in public life and of their human rights, embedding this recognition in the delivery of public services is a continuing endeavour.

iii) *Inner setting*

The *inner setting* displayed structural characteristics which would facilitate a readiness to address cancer inequalities. The social architecture of the two cancer charities was amenable to change in relation to their organisational maturity and stability in terms of staff turnover and their relative size. In contrast to the NHS, where the workforce is estimated at 1.4 million, the larger of the two charities has a workforce of 4,000 staff; the charities then, had

a sufficiently large workforce, as a realm of influence, while having a cohesive communications network through which to implement change. A further feature relates to their implementation climate: both organisations had previously engaged in work to make services accessible to other underserved communities. Each organisation tailored the intervention in ways specific to their organisational requirements.

iv) Characteristics of Individuals

The CFIR (Damschroder et al 2009) highlights the necessity for organisational change to start with individuals: the beliefs and knowledge of individual cancer professionals partly relies on their self-efficacy in making change in addition to believing they have adequate how-to knowledge and of the underlying principles. Professionals involved in this project had considerably more expertise, than the academic researcher, in cancer policy development; they were able to ensure that the recommendations in the project report were specific, achievable, included indicators of progress and were time-related. The project benefitted from the political 'savvy-ness' (Nutley et al 2008; 258) of voluntary sector organisations, through professionals' networks and contacts, their expertise in communicating key messages and their knowledge about relevance and timeliness. Their involvement enhanced the project because they were knowledgeable about other cancer policy initiatives, had understanding of policymaking processes, ensured that objectives were coherent and in the spirit of national policy initiatives and of mechanisms for the effective communication of the study's conclusions.

iv) The implementation process

The CFIR (Damschroder et al. 2009) identifies four essential activities of the implementation process that are common across models of organisational change: planning, engaging,

executing and reflecting. These steps formed an iterative and overlapping process rather than sequential and discrete stages; however, each of them are considered in turn:

Planning: The Pathways to Impact strategy identified the process of implementation from the outset. Once the project received funding, the strategy was debated in partnership group meetings so that context-specific concerns could be addressed.

Engaging: Two strategies were adopted which were tailored to the distinct needs of each of the VCS organisations. For the breast cancer charity, the approach taken focussed on producing a policy briefing, disseminating the briefing to staff, involving staff in debating the study findings through a Public Engagement event and presenting the findings to a national practitioner conference. The Public Engagement event, attended by 35 cancer nursing and other professionals and cancer service users, was held at the main offices of the charity. Professionals at the VCS took lead responsibility for this event, discussing the briefing in the context of the charity's continuing commitment to closing the gap in inequalities in breast cancer services and outcomes. The main findings of the briefing were presented: the professional outlined the reasons why the document is important from a historical, cultural and social perspective, why sexual orientation matters within healthcare, where the gaps were and how the VCS proposed to address them. Cancer service users gave accounts of their cancer journey and their experiences of service provision. Health promotion materials were developed which include images of lesbian and bisexual women and the online forum specifically welcomed the feedback from lesbian and bisexual women. The second and larger VCS provides support and care for LGBT people with any form of cancer. Following discussion, two decisions were taken which amended the implementation: the focus of the learning event was widened from LB women with breast cancer to the wider LGBT patient group. Many of the study findings were relevant for cancer professionals working across

LGBT communities with cancer and case studies were developed through the partnership group which formed the focus of the interactive workshops in the learning event. The second decision was taken to offer the learning event through the regional rather than the national networks; this necessitated building new relationships with staff who were in grassroots roles and in organisational posts which meant they were able to act as champions for the interventions.

Executing: The breast cancer charity secured the agreement of senior management to implementing the study findings and detailling changes on their public website. They developed their health promotion materials in an appropriate style so that the imagery depicted women in same-sex relationships. They undertook a programme of work to bring about a change in the culture of the organisation by:

- Developing their equality and diversity strategy by undertaking user audits of their services, using more inclusive imagery and language, working with other organizations, producing case studies, developing training on understanding the impact of discrimination on health and confidence to access services and increase the diversity of the service user involvement network;
- Collecting sexual orientation data for volunteers and plan to do so for everyone that uses the VCS's services;
- Identifying patterns of service usage and examining whether differences can be attributed to equalities issues;
- Addressing the support and informational needs of LB women with breast cancer through health promotion materials and services that are more responsive to their concerns and experiences;

- The policy briefing was used in policy and campaigns work and widely disseminated to Breast Care Specialist nurses in England and Wales, the NHS, Cancer Networks and cancer charities (300 in the nursing network, 50 cancer networks) and cancer service users. The briefing was also disseminated to lesbian, gay, bisexual and trans cancer, health and social care organisations in the UK, Australia and the USA.

The cancer support VCS was the key partner in the learning event, they badged the training as their own, took leading roles for the event, contributed to the design of the intervention resources, disseminated the resource across their workforce of 4,000 staff and developed an online training resource to accompany it. The aim was to identify enablers and barriers whereby practitioners would feel more confident in delivering care and it was important to create a safe space where professionals could ask questions and not feel judged. Presentations were delivered on research by the academic researcher; a Macmillan GP led an inter-active session on the expectations and values of cancer professionals and users and examined findings in the Cancer Patient Experience Survey (CPES) (Department of Health, 2011) which relate to LGBT cancer service users. A breast cancer service user and her carer presented her cancer journey and this highlighted some of the pressures surrounding disclosure to numerous professionals involved in her care. To signal the organisation's commitment to the project's findings, the learning event was introduced by a senior member of the VCS learning and development staff.

Reflecting: The learning event provided an opportunity both to communicate the study findings, and through three interactive workshops sought feedback from staff which was then incorporated into the good practice resource. Quantitative and qualitative feedback from the learning seminar highlighted participants' views about the process of

implementing change. These findings are analysed, using thematic analysis (Braun and Clarke, 2006), in four themes which identify the challenges in taking change forward:

(i) Understanding the distinctive needs of LGBT cancer service users

Practitioners said they were more aware of distinctive needs for LGBT when delivering care, they recognised that while LGBT service users have the same needs as all cancer service users, asking questions in a sensitive manner will contribute to enhancing the care they receive. Practitioners were also aware of the role that carers can play in cancer recovery and survival and taking account of their views and needs plays an important part in the package of care. In their evaluations, practitioners appreciated the examples given by service users of good and poor practice which gave them confidence to raise awareness among colleagues on their return to the practice setting.

(ii) Influencing the attitudes and assumptions of practitioners

Practitioners reflected on the importance of not making assumptions about service users: recognising that for some service users it is important for their longer term health and well-being if they are able to come out, whereas, others do not wish to share what they perceive to be a personal and private matter with professionals involved in their care. This recognition illustrates the meanings of personalised care for LGBT people with cancer. Practitioners at the seminar felt they had 'permission' to get it wrong as long as they were able to acknowledge their limitations and accept responsibility for mistakes and apologise. Being non-judgemental was seen to be an essential attribute of a caring professional, as well as the ability to reflect on interactions and behaviours and maintaining a commitment to providing inclusive services.

(iii) Accessing tailored information and support

There was a range of knowledge about support services in the VCS: some called for more information about the needs and experiences of LGBT people while others said they would look to collaborate with local LGBT groups in the VCS sector to provide ongoing practical and emotional support. Some valued the opportunity to find out about the range of services offered by VCS organisations, especially in the LGBT third sector, and some planned to identify funding to set up an LGBT cancer support network.

(iv) Developing the wider team

Almost all the evaluations acknowledged that change would not be embedded in their organisation if they were unable to gain the support of colleagues. Some were a little daunted by this process, fearing they would not get 'buy-in' from colleagues, while others used action oriented language: 'priorities for action', 'implement and evaluate', 'now need to translate thoughts into action', 'educating my team', 'action plans for taking this forward', 'offering training to staff' and 'empower(ing) staff to feel more confident to ensure that services and materials are tailored and inclusive'.

Discussion

Reflection on the use of PAR approaches

While only some elements of PAR methodological approaches were used in this project, the three overarching principles of: enabling action, a focus on power relationships and those being researched were actively engaged in the process. By contrast to previous user involvement in cancer research where service users were involved only in research design (Boote et al. 2010), in this KE project, users were actively involved at every stage in the

research process. In terms of power relationships, for example, the writing of the policy briefing necessitated a transfer in power and was led by a Policy Officer together with service users. Previous studies (e.g. Nolan et al. 2007) suggest that the benefits of involving service users in KE projects are threefold:

- i) *Grounded in service user experience*: The benefit of involving service users is particularly relevant for a topic that is under-investigated; their contribution ensured that the project focussed on the issues that they believed were important. Because service users were involved at every stage of the study, their insights contributed new meanings to the cancer patient experience;
- ii) *User involvement lends authority with stakeholders*: Some professionals involved in this project queried whether LB women with breast cancer constituted a patient group with distinct needs and concerns. User involvement in partnership group meetings helped to counter their invisibility in public services, cancer networks and consultation processes and enabled their voices to be heard. Service users presented their experiences at a public engagement event and at a learning seminar and these formed powerful personal testimonies about the distinctiveness of their cancer journeys;
- iii) *PAR methods are sensitive to user experiences*: Participatory approaches seek to empower research participants and users of knowledge; they pose a challenge the historic expertise of academic researchers. The research approach adopted in this KE project aimed to model the desired outcome of equality in cancer services.

In summary, the project sought to enhance the legitimacy of the two intervention resources through Participatory Approaches to Research involving service users and professionals in their development.

Reflection on implementation strategies:

The project adopted some characteristics of a 'diffusion of innovations' (Mitton et al. 2007; 735) approach, which is concerned with the spread of ideas, technologies and practices among organisations and individuals, and may lend insights for future projects concerned with research impact. Damschroder et al (2009) describe these the role taken by key individuals as 'opinion leaders' who have formal influence in an organisation and 'champions' who will dedicate themselves to driving through an implementation (Damschroder et al. 2009; 11). This project identified key individuals who fulfilled these functions: the Director of Research and the Policy Officer at the first VCS and the service user inclusion manager at the second took key roles in developing this project and their insider status gave them leverage to negotiate organisational change.

Reflection on outputs and outcomes:

Determining the degree to which research findings have impact on organisational cultures and practices is often achieved through outcome measures such as appraising the extent of attitude, behaviour and skill change of professionals working with service users. While quantitative data is often said to provide the gold standard in measuring impact (Staniszewska et al. 2008; 2011a); qualitative methods, together with a checklist or framework (e.g. Staley, 2009; Damschroder et al. 2009; Staniszewska et al. 2011b), offer the potential for critical evaluation. In the Pathways to Impact strategy document, which acted as the framework for the project, two intervention outputs were identified (the policy briefing and the good practice resource); opportunities for learning and sharing to facilitate change (the learning seminar and the online resource); and an extensive communication

and dissemination strategy to raise awareness about the research findings. In addition to the Pathways to Impact identified at the outset, one of the VCS implemented a number of organisational changes which were made publicly accessible through dedicated webpages and the second VCS held a learning event for cancer professionals. Because this is the first UK empirical study and knowledge exchange project of the cancer care needs of LB women, any policy or practice change in addressing LGBT cancer inequalities in the organisations of the partnership group were expected to be attributable to this action-oriented project.

Conclusion

Increasingly, research councils and other bodies require that the research which they fund demonstrates both scientific and societal impacts. The academic benefits of research have long been evidenced through peer-reviewed articles, conference proceedings and other publications. But the pathways to wider social impact have been less clearly articulated. This paper has sought to provide some responses to the questions posed at the start of this paper: what do we mean by research use and how do we encourage it? Characterising conceptual and instrumental knowledge as dichotomous entities seems likely to further the divide between academic and practitioner approaches to research and their attitudes to and uses of the knowledge generated. If research knowledge forms a continuum from awareness-raising to practice and policy change, then knowing about alternative ways of promoting equality in service delivery is a vital first stage in this process. But changing attitudes and perceptions involves a gradual sea-change in practitioners' values rather than a sudden storm. Moreover, the ranking system adopted by the UK Research Excellence Framework appears to place far greater value on journal impact factors rather than knowledge co-produced with practitioners and users of services (Wilkinson et al. 2012). This

paper has highlighted some of the pathways that a small ESRC funded knowledge exchange project has navigated, specifically by informing policy development; through training and practice guidance which aim to bring about benefits in research use by improving LGBT patients' experience throughout the cancer journey and providing better quality information to inform professionals' practice in UK cancer services;. LGBT health and social care research is a relatively new field of study and is thus particularly amenable to evidencing research impact. If our research goals are to contribute to improving health and quality of life, it is essential that those who are most affected are involved in the co-production of knowledge.

Key points for policy, practice and research

- The paper discusses ways of achieving impact and use of research findings in the organisation and delivery of cancer services in the voluntary sector;
- This project extends understanding about approaches to embedding LGBT equality issues in cancer care;
- It raises questions about the inclusion of LGBT health concerns in undergraduate nursing education and of the need for a policy statement about its inclusion in nursing curricula;
- It provides an overview of the use of a Participatory Action Research approach which engaged service users and stakeholders in decision-making about accessible and relevant cancer care.

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